

# Saint Louis University Journal of Health Law & Policy

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Volume 7

Issue 2 *The Future of Health Law: Exemplary  
Insight into Trending Topics*

Article 4

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2014

## Cura Personalis: A Healthcare Delivery Quandary at the End of Life

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### Recommended Citation

George P. Smith II, *Cura Personalis: A Healthcare Delivery Quandary at the End of Life*, 7 St. Louis U. J. Health L. & Pol'y (2014).

Available at: <https://scholarship.law.slu.edu/jhlp/vol7/iss2/4>

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## **CURA PERSONALIS: A HEALTHCARE DELIVERY QUANDARY AT THE END OF LIFE**

GEORGE P. SMITH, II\*

### ABSTRACT

Holistic Medicine traces its *provenance* to the foundational value or *chrism* of the Society of Jesus of *cura personalis* which directs respect be given to all individuals and to their souls — especially whenever medical healing is required. Today, the notion of best patient care should include not merely attention to somatic issues of refractory pain management but, equally, to non-somatic or existential suffering. It is at the end-stage of life that palliative — as opposed to curative — care must be provided. When a condition is seen as medically futile, this Article advocates palliative or deep sedation — when consistent with patient values — should be accepted more fully as efficacious and humane end-of-life medical care.

Roman Catholic moral theology supports the ideal that extraordinary medical measures need not be provided in order to preserve life at its end-stage. The International Association of Catholic Bioethicists acknowledged in 2011 that holistic interventions — when appropriate and consistent with best patient care — should seek to address existential or spiritual suffering by sedation.

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This essay was researched and written in draft in July-August, 2013, when I was a Visiting Scholar at the Hesburgh Center for Civil and Human Rights at the Notre Dame University School. Parts of this essay are drawn from my article entitled, *Refractory Pain, Existential Suffering and Palliative Care: Releasing the Unbearable Lightness of Being*, 20 CORNELL J.L. & POL'Y 469 (2011), and my book, GEORGE P. SMITH II, *PALLIATIVE CARE AND END-OF-LIFE DECISIONS* (2013).

I acknowledge, with sincerity, both the many professional kindnesses shown to me during my affiliation at Notre Dame by Professor Edmund P. Edmonds, Director of the Kresge Library, and his colleagues — particularly Carmela A. Kinslow, Associate Librarian — and especially the supportive friendship, over the years, given me by Professor Nell Jessup Newton, Dean of the Law School.

## I. INTRODUCTION AND OVERVIEW

Before history was ever recorded, healers have served society.<sup>1</sup> Indeed, in Western society, the provenance of healing may be traced to classical Hellenic Greece.<sup>2</sup> Other cultures have a similar history which derives from traditions which hold to the notion of “selfless service to those in need.”<sup>3</sup> From these historical glosses, it may be surmised “that whole patient care was being dispensed long before the term was coined.”<sup>4</sup> Professionalism, as a concept and in association — specifically — with medicine, has thought to have been first used by Scribonius, a Roman physician, circa 47 A.D. to mean “a commitment to compassion or clemency in the relief of suffering,”<sup>5</sup> which in turn was seen as the essence of caring for the whole person.<sup>6</sup> With the founding of the Society of Jesus by St. Ignatius of Loyola in 1541, *cura personalis* has been recognized as a foundational value or chrism of Jesuit education.<sup>7</sup> An integral part of this value is particular acknowledgment that “attention and respect [must be] given to the care of an individual person and that person’s soul.”<sup>8</sup>

Over time, the roles of curing and of healing began to be defined more distinctly between that of the physician and the patient — for, it is the physician’s knowledge and expertise which gives him more decisive power in curing.<sup>9</sup> In the healer function, however, it is the patient who becomes the center of power — since, the healing occurs within the patient who makes “the healing journey.”<sup>10</sup> Today, it is said that there is a therapeutic alliance

1. Richard L. Cruess & Sylvia R. Cruess, *Whole Person Care, Professionalism, and the Medical Mandate*, in *WHOLE PERSON CARE: A NEW PARADIGM FOR THE 21ST CENTURY* 201, 201 (Tom A. Hutchinson ed., 2011).

2. *Id.*

3. *Id.*

4. *Id.*

5. Cruess & Cruess, *supra* note 1, at 202.

6. *Id.* See GARY B. FERNGREN, *MEDICINE AND HEALTH CARE IN EARLY CHRISTIANITY* (2009).

7. See Timothy J. Cook, *Professional Educator Preparation in the Jesuit Tradition*, in *ELEMENTARY EDUCATION HANDBOOK: UNDERGRADUATE PROGRAM 5* (Lynn Olson ed., 2002), available at [http://www.creighton.edu/fileadmin/user/CCAS/departments/education/docs/ElemUG\\_Handbook.pdf](http://www.creighton.edu/fileadmin/user/CCAS/departments/education/docs/ElemUG_Handbook.pdf) (on file with the *St. Louis University Journal of Health Law and Policy*). *Cura personalis* is the founding principle of the Georgetown University Medical Center in Washington, D.C. See GEORGETOWN UNIV. *What is Cura Personalis* (2011), <http://som.georgetown.edu/about/curapersonalis>.

8. CATHARINE RANDALL, *BLACK ROBES AND BUCKSKIN* 21 (2011). See DAVID F. KELLY, GERARD MAGILL & HENK TEN HAVE, *CONTEMPORARY CATHOLIC HEALTH CARE ETHICS* 24 (2d ed. 2013). See *IMAGO DEI: HUMAN DIGNITY IN ECUMENICAL PERSPECTIVE* (Thomas Albert Howard ed., 2013).

9. Tom A. Hutchinson, *Whole Person Care*, in *WHOLE PERSON CARE: A NEW PARADIGM FOR THE 21ST CENTURY* 1, 4 (Tom A. Hutchinson ed., 2011).

10. *Id.*

between physician and patient and that a “participatory moral agency” exists.<sup>11</sup>

In 1940, rather dramatically, with the publication of Paul Tournier’s *MEDICINE DE LA PERSONNAE*,<sup>12</sup> the doctor-patient relationship was shown to be “illuminated equally by faith and by medicine.”<sup>13</sup> Tournier advanced the idea that spirituality was not only a significant vector of force in this relationship, but indeed, was complementary to the practice of medicine.<sup>14</sup> This dialogue started by Tournier, continues today<sup>15</sup> with more and more acceptance of the centrality of spiritual care to healthcare “particularly in palliative and end-of-life care, where a holistic approach is established as both a philosophy and model of care.”<sup>16</sup> Yet, even with this level of acceptance, much uncertainty and ambiguity pervade regarding the extent to which spiritual needs are addressed.<sup>17</sup>

#### A. *New Holistic Directions*

Building upon the principle of *cura personalis*, a new form of medicine, termed “systems medicine,” is developing.<sup>18</sup> Seeking to expand medical education and treatment beyond reductionism, and to outreach — holistically — in order to consider economic, ethical, and socio-legal values, systems medicine incorporates not only the biochemical and physiological but also the “environmental interactions that maintain living

11. See GEORGE P. SMITH, II, *LAW AND BIOETHICS: INTERSECTIONS ALONG THE MORTAL COIL* 138-60 (2012).

12. See PAUL TOURNIER, *MEDICINE DE LA PERSONNAE* (1940).

13. John Cox, Alastair V. Campbell & Bill Fulford, *Introduction: At the Hearth of Healing*, in *MEDICINE OF THE PERSON: FAITH, SCIENCE AND VALUES IN HEALTH CARE PROVISION* 17, 19 (John Cox et al. eds., 2007).

14. See Paul Tournier, *A DOCTOR’S CASEBOOK IN THE LIGHT OF THE BIBLE* (1954). Tournier advocated that total medical care for the whole person must include biological, psychological, social, and spiritual issues. See Hans-Rudolf Pfeifer & John Cox, *The Man and His Message*, in *MEDICINE OF THE PERSON: FAITH, SCIENCE AND VALUES IN HEALTH CARE PROVISION* 33 (John Cox et al. eds., 2007). See Gary B. Ferngren, *Medicine and Religion: A Historical Perspective*, in *OXFORD TEXTBOOK OF SPIRITUALITY IN HEALTHCARE* 3 (Mark Cobb, Christine M. Puchalski & Bruce Rumbold eds., 2012). See GEORGE P. SMITH, II, *THE CHRISTIAN RELIGION AND BIOTECHNOLOGY: A SEARCH FOR PRINCIPLED DECISION-MAKING* (2005).

15. See George P. Smith, II, *Law, Medicine, and Religion: Towards a Dialogue and Partnership in Biomedical Technology and Decisionmaking*, 2 J. CONTEMP. HEALTH L. & POL’Y 169, 169 (2005) (showing how the conversation continues to this day).

16. Elizabeth Mackinlay, *Care of Elderly People*, in *OXFORD TEXTBOOK OF SPIRITUALITY IN HEALTHCARE* 251, 261 (Mark Cobb, Christine M. Puchalski & Bruce Rumbold eds., 2012).

17. *Id.* See Grace Davie & Martyn Percy, *The Future of Religion*, in *OXFORD TEXTBOOK OF SPIRITUALITY IN HEALTHCARE* 482 (Mark Cobb, Christine M. Puchalski & Bruce Rumbold eds., 2012).

18. Howard J. Federoff & Lawrence O. Gostin, *Evolving from Reductionism to Holism: Is There a Future for Systems Medicine*, 302 JAMA 994, 994 (2009).

organisms.”<sup>19</sup> While purporting to account for a multitude of complex vectors in disease prediction, a substantial challenge remains in actually quantifying multiple factors such as environmental ones.<sup>20</sup> Systems medicine holds the promise of “greater precision in diagnosis, opportunity for earlier intervention, risk-based prevention, individualization of care, and optimization of the patient-client interface.”<sup>21</sup>

#### B. *Hospice and Palliative Care*

“Total pain” management of physical, psychological, and spiritual suffering was — since the beginnings of the modern hospice movement led by Dame Cicely Saunders in 1967 — the express goal of hospice care,<sup>22</sup> just as it is today.<sup>23</sup> Indeed, palliating the whole person within an environment of compassionate support is central to sound hospice care and, thus, seeks to “humanize medicine.”<sup>24</sup>

The World Health Organization (WHO) defined palliative care as that which “improves the quality of life for patients and families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life, and bereavement.”<sup>25</sup> Palliating the whole person — then — requires medicine to attend more fully to existential suffering. For this type of palliation to be efficacious, healthcare decision makers must regularly reassess patient treatment goals in order to not only learn how their patients define and experience pain, but the patients’ thresholds for tolerating various sources of distress.<sup>26</sup> These thresholds are seen as being informed by a patient’s personality, which has,

19. *Id.*

20. *Id.* at 995.

21. *Id.* at 996. See Charles L. Bards, *Defining ‘Patient-Centered’ Medicine*, 366 NEW ENG. J. MED. 782, 782 (2012).

22. See Cicely Saunders, *Hospice*, 1 MORTALITY 317, 320 (1996).

23. See HOSPICE: THE LIVING IDEA (Cicely Saunders et al. eds., 1981). See also GEORGE P. SMITH, II, *PALLIATIVE CARE AND END-OF-LIFE DECISIONS* (2013).

24. See HOSPICE CARE ON THE INTERNATIONAL SCIENCE 7 (Cicely Saunders & Robert Kastenbaum eds., 1997). See also Martha L. Twaddle, *Hospice Care*, in DIGNITY AND DYING: A CHRISTIAN APPRAISAL 183, 189 (John F. Kilner, Edmund D. Pellegrino & Arlene B. Miller eds., 1996).

25. *Palliative Care*, WORLD HEALTH ORG., <http://www.who.int/cancer/palliative/en> (last visited Apr. 20, 2013). See Peter Whoriskey & Dan Keating, *In Hospice, but not Dying*, WASH. POST, Dec. 27, 2013, at 1A (reporting on the growing \$17 billion hospice industry dominated by for-profit corporations which are competing aggressively and recruiting patients not actually dying, thereby increasing the length of Medicare covered stays and then discharging the patients who are seen as “hospice survivors” and then live extended periods of time).

26. See Martin J. Fegg et al., *Personal Values and Individual Quality of Life in Personal Values and Individual Quality of Life Palliative Care Patients*, 30 J. PAIN & SYMPTOM MGMT. 154 (2005).

in turn, been shaped by life experiences and attitudes toward death management and quality of life in end-stage illness.<sup>27</sup>

### C. *Managing End-Stage Illness*

“Managing” death at the end-stage of life when a futile medical condition exists, presents linguistic, moral, and philosophical ambiguities regarding the voluntary cessation of nutrition, hydration, palliative or terminal sedation, physician-assisted suicide, and voluntary euthanasia.<sup>28</sup> Although these actions are distinct, there is a central and unifying commonality among them — specifically, their common purpose of hastening a humane death, thereby showing compassion to those experiencing refractory pain and existential suffering.<sup>29</sup>

The purpose of this Article is to argue, and to advance the notion, that existential suffering is as valid a consideration as physical pain is at the end-stage of life. Because of this relationship, greater attention must be given by medicine to palliating the whole person and to accepting the validity of palliative sedation. As efficacious and compassionate treatment when appropriate,<sup>30</sup> laws should — similarly — accommodate the necessity for this procedure as its use becomes warranted under a theory of adjusted care.<sup>31</sup> Further, the law should validate palliative sedation as humane end-of-life medical treatment and should not complicate, and thereby hinder, what are sound medical responses — consistent with patient values — to alleviating conditions deemed medically futile.<sup>32</sup> Legislation allowing for death with dignity as enacted in Oregon,<sup>33</sup> Washington,<sup>34</sup> and Vermont<sup>35</sup> is

27. *Id.* See FIONA RANDALL & ROBIN DOWNIE, *END OF LIFE CHOICES: CONSENSUS AND CONTROVERSY* (2009).

28. See STEVEN LUPER, *THE PHILOSOPHY OF DEATH* (2009). Society may be seen as moving from an absolute sanctuary of life view to a standard of quality of life when it accepts the Principle of Double Effect, refusals of treatment, and palliative or terminal sedation. JOHN B. MITCHELL, *UNDERSTANDING ASSISTED SUICIDE: NINE ISSUES TO CONSIDER* 23 (2007).

29. See George P. Smith, II, *Refractory Pain, Existential Suffering, and Palliative Care: Releasing an Unbearable Lightness of Being*, 20 CORNELL J.L. & PUB. POL’Y 469, 479 (2011).

30. See George P. Smith, II, *Terminal Sedation as Palliative Care: Revalidating a Right to a Good Death*, 7 CAMBRIDGE Q. HEALTHCARE ETHICS 382, 382 (1998).

31. Smith, *supra* note 29, at 475. A continuum of adjusted care commences from the initial diagnosis through the end-stage of illness and is modified, then, medically and palliatively as deemed necessary to accommodate the best interests of the patient to avoid pain and suffering and thus receive compassionate care. See DAVID C. THOMASMA, *HUMAN LIFE IN THE BALANCE* 211 (1990). See also Joanne Kenen, *A New Focus on Easing Pain: Palliative Care Helps the Very Ill, It May Also Keep Costs Down*, WASH. POST, July 3, 2007, at F1.

32. See JENNIFER RUGER, *HEALTH AND SOCIAL JUSTICE* 183-84 (2009).

33. OR. REV. STAT. ANN §§ 127.800(12), 127.805 (West 2005).

34. WASH. REV. CODE § 70.245(13) (2009).

— outside of state judicial action validating assistance in dying when a futile medical condition exists<sup>36</sup> — the most sensible approach toward achieving social justice.<sup>37</sup>

## II. BEST PATIENT CARE

The President's Council on Bioethics concluded in 2005 that the basic standard for clinical decision-making should be one which promotes the best patient care.<sup>38</sup> This standard obviously must be continually adjusted as a patient's case history progresses,<sup>39</sup> and to promote patient care anchored in mercy, compassion, beneficence, and loving charity — care which recognizes that relief of pain is the most universal moral obligation that a physician must uphold and that there is, indeed, a right not to suffer.<sup>40</sup>

Psychological distress, or existential pain, however, is usually difficult to assess because evaluation requires special training and continual contact with the patients' families.<sup>41</sup> There is a general societal aversion to the obstacles faced in proving a patient's emotional distress at end-of-life care.<sup>42</sup> Distinguishing between depression and psychological morbidity is difficult because the symptomology of disrupted sleeping patterns, loss of energy, and lack of appetite are not exclusive response mechanisms to psychological distress, but appear in cancer and other terminal illnesses as

35. VT. STAT. ANN. tit. 18, § 5281(10) (West 2013).

36. See *Baxter v. State*, 224 P.3d 1211 (Mont. 2009) (where, while declining to declare a constitutional right to die with dignity, the Montana Supreme Court held that physicians aid in dying was not violating the Rights of the Terminally Ill Act, nor against any state public policy forbidding such conduct).

37. See GEORGE P. SMITH, II, *DISTRIBUTIVE JUSTICE AND THE NEW MEDICINE* 38-47 (2008). See also Katy Butler, *A Full Life to the End*, WALL ST. J., Sept. 7, 2013, at C1 (urging autonomous healthcare decisions be made in anticipation of medical crises so that use of medical technologies given routinely to individuals over 80 facing healthcare emergencies in intensive care units can be forestalled).

38. PRESIDENT'S COUNCIL ON BIOETHICS, *TAKING CARE: ETHICAL CAREGIVING IN OUR AGING SOCIETY* 217 (2005), available at [http://bioethics.georgetown.edu/pcbe/reports/taking\\_care/taking\\_care.pdf](http://bioethics.georgetown.edu/pcbe/reports/taking_care/taking_care.pdf). Best patient care is adjusted to the developing medical needs of the patient. Essential to the standard of best care is acceptance of the "intrinsic dignity of persons" which, in turn, mandates that the goal of providing care must be to enhance total patient well being (somatic and non-somatic) and, at the end of life demonstrate beneficence, compassion, or charity in managing pain and suffering.

39. DAVID C. THOMASMA & GLENN C. GRABER, *EUTHANASIA: TOWARD AN ETHICAL POLICY* 129 (1991).

40. *Id.* at 193-94 (quoting Dr. Edmund D. Pellegrino).

41. Manish Agrawal & Ezekial J. Emmanuel, *Attending to Psychological Symptoms and Palliative Care*, 20 J. CLINICAL ONCOLOGY 624, 624 (2001).

42. *Id.*

well.<sup>43</sup> Because of these difficulties and uncertainties, the palliative management of existential pain has been largely neglected.<sup>44</sup>

While no general “solutions” exist for meeting the existential needs of terminally ill patients, attempts to meet these needs require careful listening skills and defined lines of communication between healthcare providers, patients, affected families, and proxy or surrogate decision makers. Valid existential concerns are often obscured during palliative care treatment.<sup>45</sup> Even though a patient may have no absolute control over the wide and varied spectra of suffering, the patient still has freedom to choose what attitude is taken toward that suffering.<sup>46</sup> By extending end-of-life care to include psychiatric, psychological, existential, and spiritual issues — consistent with the WHO’s definition of palliative care and its goal of addressing total patient needs<sup>47</sup> — a more complete, compassionate, and realistic approach to managing terminal illness and end-stage suffering would be implemented.<sup>48</sup>

### III. ASSESSING PAIN

While pain is properly seen as biological and measurable, it is — inherently — subjective, individual, and variable.<sup>49</sup> Consequently, there is no clear understanding whether mental suffering and mental pain are, indeed, “equivalent or identical concepts and experiences.”<sup>50</sup> Interestingly, some research has even suggested that the same brain regions involved in assessing physician pain are also found in a number of forms of actual emotional distress.<sup>51</sup> The central issue confronting law is how to deal with the “externally verifiable reality” of pain.<sup>52</sup> What level of exculpation should be granted by the state to those attending to the anguish and suffering of those at the end-stage of life.<sup>53</sup> Can pain and suffering in death be likened

43. *Id.*

44. *Id.*

45. Ingrid Bolmsjo et al., *Meeting Existential Needs in Palliative Care—Who, When, and Why?*, 18 J. PALLIATIVE CARE 185 (2002).

46. William Breitbart et al., *Psychotherapeutic Interventions at the End of Life: A Focus on Meaning and Spirituality*, 49 CAN. J. PSYCHIATRY 366, 371 (2004).

47. See HOSPICE, *supra* note 23. See Jane E. Brody, *The Treatment that Respects Pain*, N.Y. TIMES, Dec. 3, 2013, at D7 (reporting on the uses of palliative care in hospice).

48. See Breitbart et al., *supra* note 46, at 371.

49. Amanda C. Pustilnik, *Pain as Fact and Heuristic: How Pain Neuroimaging Illuminates Moral Decisions of Law*, 97 CORNELL L. REV. 801, 805-06, 810-11 (2012).

50. *Id.* at 825 n.93.

51. *Id.*

52. *Id.* at 803. Pain neuroimaging, or more precisely functional magnetic resonance imaging (fMRI) is being used to measure pain. *Id.* at 846.

53. *Id.* at 817-25; Smith, *supra* note 29, at 515-24.



to the state's responsibility to safeguard its citizens from suffering cruel and unusual punishment?<sup>54</sup>

Although existential pain has been defined as suffering "with no clear connection to physical pain," it has been recognized — nonetheless — as suffering,<sup>55</sup> which in fact, can be expressed as physical pain. Today, existential pain is seen, commonly, as an important clinical factor either reinforcing existing pain or, serving as the root cause of it.<sup>56</sup>

#### A. *Existential Suffering*

The desire to hasten death arises because of a number of conditions: inadequate pain management, psychological conditions ranging from depression and hopelessness, to fears of loss of autonomy and physical functioning,<sup>57</sup> to futile and unbearable suffering, and avoidance of humiliation.<sup>58</sup> All of these conditions conduce to one overriding fear: loss of human dignity,<sup>59</sup> which brings with it a fear of being forced to become but a "passive bystander" to all of the normal functions of life.<sup>60</sup>

#### B. *Death Anxiety*

Coping with death anxiety or, in other words, the "untarnished awareness of death," often brings into play psychological mechanisms such as denial-based strategies of suppression, repression, and new emphases on religious beliefs which "detoxify" death itself.<sup>61</sup> Existential terror is, then, sought to be managed spiritually by embracing the notion that life is, truly

54. See JONATHAN HERRING, *Ethic of Care*, in *CARING AND THE LAW* 46 (2013); SMITH, *supra* note 23. See also George P. Smith, II, *Utility and the Principle of Medical Futility: Safeguarding Autonomy and the Prohibition Against Cruel and Unusual Punishment*, 12 J. CONTEMP. HEALTH L. & POL'Y 1 (1996) [hereinafter Smith, *Utility and the Principle of Medical Futility*]; GEORGE P. SMITH, II, *FINAL EXISTS: SAFEGUARDING SELF-DETERMINATION AND THE RIGHT TO BE FREE FROM CRUEL AND UNUSUAL PUNISHMENT* (1997) (on file with author).

55. Peter Strang et al., *Existential Pain—An Entity, or Provocation, or a Challenge?*, 27 J. PAIN & SYMPTOM MGMT. 241, 245 (2004).

56. *Id.* at 247.

57. Helene Starks et al., *Why Now? Timing and Circumstances of Hastened Deaths*, 30 J. PAIN & SYMPTOM MGMT. 212, 216 (2005).

58. Gerrit van der Wal & Robert J. M. Dillmann, *Euthanasia in the Netherlands*, 308 BRIT. MED. J. 1346, 1347 (1994).

59. DEREK HUMPHRY, *FINAL EXISTS: THE PRACTICALITIES OF SELF-DELIVERANCE AND ASSISTED SUICIDE FOR THE DYING* 56 (2002).

60. Richard B. Gunderman, *Is the Enemy?*, HASTINGS CTR. REP. 40, 42 (2002). See Edmund D. Pellegrino, *Euthanasia and Assisted Suicide*, in *DIGNITY AND DYING: A CHRISTIAN APPRAISAL* 105 (John F. Kilner et al. eds., 1996).

61. See IRVIN D. YALOM, *EXISTENTIAL PSYCHOTHERAPY* 110-11 (1980). See also Stephen Liben, *Empathy, Compassion, and the Goals of Medicine*, in *WHOLE PERSON CARE: A NEW PARADIGM FOR THE 21ST CENTURY* 59, 59 (Tom A. Hutchinson ed., 2011).

meaningful, which in turn has the effect of enriching cultural attitudes of self-esteem.<sup>62</sup> By creating opportunities for individuals to create positive societal experiences for themselves, their uniqueness, value, and even spiritual immortality serves, ideally, to mitigate the dread of death.<sup>63</sup>

In approximately twenty-five percent of all terminally ill patients, depression and other mood disorders occur.<sup>64</sup> Yet, interestingly, few receive pharmacological aid through anti-depressant prescriptions.<sup>65</sup> As this Article shows, the main obstacle to a more liberal response to these patients' needs is the lack of clarity in determining when a distressed, terminal patient is suffering from clinical depression or, instead, exhibiting a "normal grief response" to the dying process.<sup>66</sup> The components of both of these syndromes are often vague, imprecise, and difficult to evaluate.<sup>67</sup> Commonly, when patients are obsessed with feelings of worthlessness, they lose their ability and desire to interact socially, and — indeed — lose their sense of hope they are properly assessed as suffering from clinical depression<sup>68</sup> and should be given whatever dosage of analgesics is deemed necessary to alleviate that condition — because pharmacotherapy is ultimately the principal tool for symptom control.<sup>69</sup>

Another drawback to accurate and prompt evaluations of psychological distress or existential suffering is often the inability of a physician or palliative care management team to understand patient views about suffering. As a spiritual phenomenon, suffering is often accepted in Christian communities as a meaningful and authentic community response to Jesus Christ's own

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62. Sheldon Solomon & Krista Lawlor, *Death Anxiety: The Challenge and the Promise of Whole Person Care*, in *WHOLE PERSON CARE: A NEW PARADIGM FOR THE 21ST CENTURY* 97, 98 (Tom A. Hutchinson ed., 2011). See YOLAM, *supra* note 61, at 208 ("[A] sense of fulfillment, a feeling that life has been well lived, mitigates against the terror of death."). See also, James F. Bresnahan, *The Catholic Art of Dying*, *AM.*, Nov. 4, 1995, at 12, 13.

63. "A person may come to the moment of death full of bitterness, anger, fear, vanity, jealousy, greed and pride. A life lived this way may lead to a death died that way" — for, in a very real way, "[d]eath is a punctuation mark on a person's life . . . the end of a long spiritual journey." Daniel P. Sulmasy, *Health the Dying: Spiritual Issues in the Care of the Dying Patient*, in *THE HEALTH CARE PROFESSIONAL AS FRIEND AND HEALER: BUILDING ON THE WORK OF EDMUND D. PELLEGRINO* 188, 195-96 (David C. Thomasma & Judith Lee Kissell eds., 2000).

64. Karl E. Miller et al., *Antidepressant Medication Use in Palliative Care*, 23 *AM. J. HOSPICE & PALLIATIVE MED.* 127, 127 (2006).

65. *Id.*

66. *Id.*

67. *Id.* at 128.

68. *Id.*

69. Arthur G. Lipman, *The Scream by Edvard Munch: A Profound Portrayal of Existential Suffering*, 19 *J. PAIN & PALLIATIVE CARE PHARMACOTHERAPY*, no. 1, 2005, at 1, 2.

suffering.<sup>70</sup> In some faith communities, cultural efforts are expanded in order to view suffering — physically and mentally — as a positive, reinforcing value. Merely accepting suffering as authentic, however, does not mean that it is also meaningful.<sup>71</sup> It remains for the physician to ascertain and then listen carefully to the spiritual parameters within each patient's character<sup>72</sup> in an attempt to treat those seriously ill as whole persons.<sup>73</sup> In this way, the therapy is truly patient-centered.<sup>74</sup>

Refractory existential suffering — or those symptoms which defy adequate control despite all efforts to provide relief — is difficult to distinguish during the end-stages of life from physical distress.<sup>75</sup> Those additional refractory symptoms most commonly reported as requiring palliative sedation are: various degrees of agitation, restlessness or distress, confusion, respiratory distress, pain, and myoclonus (e.g., severe twitching, jerking or uncontrollable shakes).<sup>76</sup>

Existential care is more often than not left to the nursing staff.<sup>77</sup> Even in the daily hospital bed environment, however, the nursing staff must possess a special level of sensitivity to understand patients' indirect questions regarding the depth and severity of their distress over their terminal illness. Once understood, it typically falls upon the nurses to devise a procedure for providing empathetic support.<sup>78</sup> Palliative sedation therapy is thus defined as "the use of sedative medications to relieve intolerable and refractory distress by the reduction in patient consciousness."<sup>79</sup> When patient suffering — physical or existential — become refractory to standard palliative therapies, the humane, compassionate, and merciful response is to offer palliative or

70. Stan Van Hooft, *The Meanings of Suffering*, HASTINGS CENTER REP., Sept.-Oct. 1998, at 13, 15.

71. *Id.* at 14.

72. *Id.* at 15. See Martha D. M. Fowler, *Suffering*, in DIGNITY AND DYING: A CHRISTIAN APPRAISAL 44 (John F. Kilner et al. eds., 1996).

73. See Seth M. Holmes et al., *Screening the Soul: Communication Regarding Spiritual Concerns Among Primary Care Physicians and Seriously Ill Patients Approaching the End of Life*, 23 AM. J. HOSPICE & PALLIATIVE MED. 25, 25 (2006).

74. Alton Hart Jr. et al., *Hospice Patients' Attitudes Regarding Spiritual Discussions with Their Doctors*, 20 AM. J. HOSPICE & PALLIATIVE MED. 135, 138 (2003).

75. Bernard Lo & Gordon Rubinfeld, *Palliative Sedation in Dying Patients*, 294 JAMA 1810, 1812 (2005).

76. *Id.* at 1811.

77. Rob Houtepen & David Hendriks, *Nurses and the Virtues of Dealing with Existential Questions in Terminal Palliative Care*, 10 NURSING ETHICS 377, 387 (2003).

78. Houtepen & Hendriks, *supra* note 77, at 377. See Liben, *supra* note 61, at 59.

79. Tatsuya Morita et al., *Definition of Sedation for Symptom Relief: A Systematic Literature Review and a Proposal for Operational Criteria*, 24 J. PAIN & SYMPTOM MGMT. 447, 447 (2002).

terminal sedation.<sup>80</sup> This approach to medical treatment may be seen as consistent with sound principles of adjusted care.<sup>81</sup>

### C. Demoralization

It has been suggested that — in the clinical setting of hospice or palliative care — a unique diagnostic category, termed the “demoralization syndrome,” is becoming more recognizable and should be refined and classified as a cognitive disorder.<sup>82</sup> Seen as a “useful category of existential distress in which meaningless predominates and . . . profound hopelessness and [a] desire to die may result,”<sup>83</sup> this syndrome, if not treated satisfactorily with pharmacological therapy, should render such a demoralized patient incompetent to make medical decisions.<sup>84</sup>

Yet, interestingly, there is no conclusive empirical evidence to support an all too popular conclusion that depression so impairs judgment as to prevent one from competently disapproving of the initiation or cessation of medical treatment.<sup>85</sup> Sadly, this depression argument would appear to be a ruse to obstruct and even prevent end-of-life decision-making on the grounds of moral repugnancy to alternative or surrogate healthcare providers.<sup>86</sup>

If — and when — the demoralization syndrome is accepted by diagnosticians as a cognitive disorder, it would then remain for physicians to respond with compassion and care in remediating this medical condition. If deemed proper, under the overarching principle of medical futility, physicians should consider the reasonableness of alleviating this pathological mental state in the end-stage patient by administering palliative or terminal sedation. Such a course of treatment would be consistent with the central obligations of all physicians to alleviate pain and suffering —

80. Paul Rosseau, *Existential Suffering and Palliative Sedation: A Brief Commentary with a Proposal for Clinical Guidelines*, 18 AM. J. HOSPICE & PALLIATIVE MED. 151, 151-52 (2001).

81. See THOMASMA, *supra* note 31, at 165, 185. See also Roger S. Magnusson, *The Devil's Choice: Re-Thinking Law, Ethics, and Symptom Relief in Palliative Care*, 34 J.L. MED. & ETHICS 559, 566 (2006) (arguing for a legal defense of necessity be allowed when symptom relief is ineffective and palliative interventions shorten the life of a patient).

82. Harold I. Schwartz, *Death Row Syndrome and Demoralization: Psychiatric Means to Social Policy Ends*, 33 J. AM. ACAD. PSYCHIATRY L. 153, 154 (2005).

83. David W. Kissane, *The Contribution of Demoralization to End of Life Decisionmaking*, 34 HASTINGS CTR. REP. 21, 23 (2004).

84. *Id.* at 29.

85. RONALD A. LINDSAY, *FUTURE BIOETHICS: OVERCOMING TABOOS, MYTHS, AND DOGMAS* 111 (2008).

86. *Id.* at 112.

here, mental suffering — and to assure the dying patient's dignity and best interests.<sup>87</sup>

#### D. *Early Terminal Sedation*

As contentious as palliative or terminal sedation is, early terminal sedation (ETS) is even more inflammatory for some — but for others, it is seen as a progressive and humane treatment.<sup>88</sup> Under this procedure, a patient — with consent — is sedated before “actively dying.”<sup>89</sup> As such, the process combines palliative sedation with a cessation of nutrition and hydration.<sup>90</sup> The distinction between ETS and palliative sedation is that in the former, patients are capable of receiving alimentation and hydration orally or parenterally but exercise their right to refuse this treatment. In causing palliative or terminal sedation, however, sedation is administered to those for whom nutrition and hydration are no longer life-sustaining.<sup>91</sup> Often analogized — incorrectly to assisted suicide — ETS should be viewed as but “translating” the choice of a patient to refuse nutrition and hydration by the patient with deep, continuous sedation.<sup>92</sup>

Given prognostic uncertainties on the progression of certain chronic diseases — and the desire of some patients to exercise their right of autonomy by managing their end-stage care, it has been predicted that ETS will rise<sup>93</sup> — especially so, as dementia cases rise within the population and patients wish to act before their cognitive powers are lost.<sup>94</sup> Presently in America, there are more than five million Americans who have Alzheimer's disease — and this figure could be tripled by 2050.<sup>95</sup> Indeed, someone is diagnosed with this disease every sixty-eight seconds.<sup>96</sup>

87. THOMASMA & GRAEBER, *supra* note 39, at 192, 194 (quoting Dr. Edmund D. Pellegrino). See Pellegrino, *supra* note 60.

88. See Victor Cellarius, *Early Terminal Sedation is a Distinct Entity*, 25 BIOETHICS 47 (2011).

89. *Id.* at 47, 50-52, 54.

90. *Id.*

91. *Id.* See Lois Shepherd, *In Respect of People Living in a Permanent Vegetative State—And Allowing Them to Die*, 16 HEALTH MATRIX 631 (2006).

92. Cellarius, *supra* note 88, at 51.

93. *Id.* at 48. See Magnusson, *supra* note 81.

94. Rosemary Bennett, *Aided Suicide will Increasingly be Choice of Dementia Patients*, THE TIMES, May 31, 2013, at 12.

95. See ALZHEIMER'S ASSOCIATION, [http://www.alz.org/alzheimers\\_disease\\_facts\\_and\\_figures.asp](http://www.alz.org/alzheimers_disease_facts_and_figures.asp) (last visited Apr. 5, 2013).

96. *Id.*

## IV. ROMAN CATHOLIC PERSPECTIVES: HOLISTIC MEDICINE COMPATIBILITIES

Catholic moral theology has never accepted the notion that “human life must be sustained at virtually all costs.”<sup>97</sup> Even though the sanctity and sacredness of all life is a given, the Catholic tradition acknowledges “the ethical import of at least some degree of quality of life,” and further accepts “at some point, a lack of quality means that life can be let go.”<sup>98</sup> This compassionate approach to a theology of human life in healthcare ethics is given focus and application in the distinction drawn between ordinary and extraordinary ends taken to preserve life.<sup>99</sup>

Taking its foundational roots from positions taken by His Holiness Pope Pius XII in the 1940’s and 1950’s, the Catholic position is that “it is never obligatory to make use of medical measures that are morally extraordinary in order to preserve life.”<sup>100</sup> Indeed, the 1994 Catechism of The Catholic Church states unequivocally that, “[i]f morality requires respect for the life of the body, it does not make it an absolute value.”<sup>101</sup> Withdrawing or withholding medical treatments are not acts of killing; for, they merely “allow a patient to die of the underlying condition.”<sup>102</sup> While these courses of action may not be “always morally right,” the act of allowing one to die is morally valid “when it is the foregoing of morally extra treatment.”<sup>103</sup>

97. KELLY, MAGILL & TEN HAVE, *supra* note 8, at 33.

98. *Id.* See George P. Smith, II, *Quality of Life, Sanctity of Creation: Palliative or Apotheosis?*, 63 NEB. L. REV. 709 (1984). See also MITCHELL, *supra* note 28. But see Kevin D. O’Rourke, *Physician Assisted Suicide: A Religious Perspective*, 15 ST. LOUIS U. PUB. L. REV. 433 (1996).

99. KELLY, MAGILL & TEN HAVE, *supra* note 8, at 33. Held to be a doctrine or, alternatively, applied as a rule, the principle of double effect is grounded in Roman Catholic philosophy and moral theology. It endeavors to structure specific guidelines to aid in determining when, ethically, to pursue a course of action to achieve a good end (here, the reduction of pain and suffering at the end-stage of life) — notwithstanding the full comprehension of the fact that bad results (e.g., death, possibly) may well flow from the initiating conduct. See Daniel P. Sulmasy & Edmund D. Pellegrino, *The Rule of Double Effect: Clearing Up the Double Talk*, 159 ANNALS INTERNAL MED. 545, 547 (1999). See also MITCHELL, *supra* note 28, at 23 (acknowledging the doctrine as giving “moral sanction to well-intended, good actions that turn out to have bad effects”). But see Magnusson, *supra* note 81 (criticizing the imprecision of applying the principle of double effect).

100. KELLY, MAGILL & TEN HAVE, *supra* note 8, at 33.

101. *Id.* at 33.

102. *Id.* Nothing in the Christian tradition bind either patients or physicians to pursue treatments considered excessively burdensome or futile and confer benefits “disproportionate to the burdens it imposes” — be they “physical, emotional or fiscal.” Autonomy, within the Christian view, “permits refusing such disproportionate treatments directly or through a living will, durable power of attorney, or a ‘do not resuscitate’ order.” Pellegrino, *supra* note 60, at 114. See also John F. Kilner, *Forgoing Treatment*, in DIGNITY AND DYING: A CHRISTIAN APPRAISAL 69 (John F. Kilner, Edmund D. Pellegrino & Arlene B. Miller eds., 1996).

103. KELLY, MAGILL & TEN HAVE, *supra* note 8, at 134.

There is ethically and legally no reason to distinguish between withholding and withdrawing — even though they may indeed “feel different.”<sup>104</sup> When a moral distinction is sought to be drawn between the withholding of treatment and of the withdrawal of it, however, greater blame is often attached to the former rather than the latter.<sup>105</sup> Consequently, when situations of this character arise, even though medically appropriate to commence treatment, physicians become reluctant — if not unwilling — to act in order to avoid ending it when, subsequently, it becomes inappropriate.<sup>106</sup> Regrettably, the net effect of this quandary results in under-treating at-risk patients.<sup>107</sup>

Inasmuch as the standard of medical care permits the alleviation of physical pain for the dying patient,<sup>108</sup> it is also valid — morally and legally — to act in this manner.<sup>109</sup> Indeed, the medical community has long asserted that the use of sedatives is not ever intended directly to hasten death.<sup>110</sup> Proper pain management may never be rejected by surrogate decision makers when patients “are not capable of deciding for themselves.”<sup>111</sup> For the surrogate to take this position “would be against the best interests of the patient.”<sup>112</sup>

#### A. Catholic Bioethicists Recommendations

Forty-nine signatories of a colloquium organized by the International Association of Catholic Bioethicists (IACB) in 2011 issued a powerful

104. *Id.* See Daniel Callahan, *Terminal Sedation and The Artefactual Fallacy*, in *TERMINAL SEDATION: EUTHANASIA IN DISGUISE* 93 (Torbjorn Tannsjo ed., 2004) (concluding that actions which withdraw nutrition and hydration are legitimate).

105. FIONA RANDALL & ROBIN S. DOWNIE, *PALLIATIVE CARE ETHICS: A GOOD COMPANION* 74 (1996).

106. *Id.*

107. *Id.*

108. KELLY, MAGILL & TEN HAVE, *supra* note 8, at 135.

109. *Id.*

110. Glenys Williams, *The Principle of Double Effect and Terminal Sedation*, 9 *MEDICAL L. REV.* 41, 46 (2001). See Richard A. McCormick, *Theology and Bioethics*, in *THE HEALTH CARE PROFESSIONAL AS FRIEND AND HEALER: BUILDING ON THE WORK OF EDMUND D. PELLEGRINO* 244, 254-55 (David C. Thomasma & Judith Lee Kissell eds., 2000) (discussing how “faith informs reason” and — as such — influences bioethical decision making and thus validates the conclusion made by His Holiness Pope Pius XII in his address to the International Congress of Anesthesiologists in 1952 that not all medical means must be used to preserve the end-stage of life (citing Pope Pius XII, 49 *ACTA APOSTOLICAE SEDIS* 1031-32 (1957))).

111. KELLY, MAGILL & TEN HAVE, *supra* note 8, at 238.

112. *Id.* at 238-39. See also Jonathan Herring, *Forging a relational approach: Best Interests or Human Right?*, 13 *MEDICAL L. INT'L.* 32 (2013).

statement which is germane to this present analysis.<sup>113</sup> Four central conclusions reached were that:

1. Society needs “to collaborate in providing and promoting the best possible holistic care of persons who are seriously ill or dying . . . so that their physical, psychological, existential, social, and spiritual needs can be appropriately addressed.”<sup>114</sup>
2. The same standards of “good therapeutic practice that inform other areas of health care” should guide any and all treatment decisions for the seriously ill and the dying.<sup>115</sup>
3. A relationship between healthcare providers and those seriously ill or dying patients whom they are treating grounded in trust and benevolence promotes competent and ethical care.<sup>116</sup>
4. Existential or “Spiritual” Suffering should be acknowledged and addressed accordingly by utilizing those “holistic interventions” deemed appropriate to the individual case.<sup>117</sup> “Mild to moderate levels of sedation might . . . be appropriate in some instances when existential [suffering] is refractory.”<sup>118</sup>

What is seen by this statement is the medical, ethical, philosophical, and spiritual acknowledgement that these four disciplines are symbiotic if not complementary and not antagonistic in both their quest and their application to addressing (and thereby managing) the somatic and nonsomatic, or existential pain and suffering of individuals holistically. Indeed, it is an uppermost duty of the state, itself, to safeguard its citizenry from cruel and unusual punishment and promote Social Justice through accessible healthcare.<sup>119</sup>

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113. International Association of Catholic Bioethicists, *The Use of Sedatives in the Care of Persons Who are Seriously Ill or Dying: Ethical Distinctions and Practical Recommendations*, 12 NAT’L CATH. BIOETHICS Q. 494, 494-501 (2012).

114. *Id.* at 500.

115. *Id.* at 497. See Edmund D. Pellegrino, *Doctors Must Not Kill*, in EUTHANASIA: THE GOOD OF THE PATIENT, THE GOOD OF SOCIETY 27, 32 (Robert I. Misbin ed., 1992) (where, while not denying the understandable grounds for request of terminally ill patients to hasten their deaths, Dr. Pellegrino eschews assisted suicide or active euthanasia and – instead – stresses the obligation of physicians to “practice competent analgesia, to understand why the patient requests death, and to deal with and remove those reasons in a program of palliative care”).

116. International Association of Catholic Bioethicists, *supra* note 113, at 497-98.

117. *Id.* at 498.

118. *Id.* See Pellegrino, *supra* note 115.

119. See generally ROSAMOND RHODES, MARGARET P. BATTIN & ANITA SILVERS, *MEDICINE AND SOCIAL JUSTICE: ESSAYS ON THE DISTRIBUTION OF HEALTH CARE* (2d ed. 2012) (outlining the importance to access to healthcare). See Smith, *supra* note 14. See also HERRING, *supra* note 54, at 88-151; Abdu’l-Missagh Ghadian, *Spiritual Dimensions of the Whole Person*, in



## V. CONCLUSIONS

The whole person care paradigm is, perhaps, the greatest challenge to healthcare management in the twenty-first century; and, at the same time, holds the greatest promise for realization.<sup>120</sup> Death anxiety and existential concerns challenge not only patients, but health professionals<sup>121</sup> and patients' families as well.<sup>122</sup> Indeed, non-somatic suffering is just as significant as somatic pain at all levels of society.<sup>123</sup> Physicians and other healthcare providers "need to recognize how their own non-conscious death fears, combined with the abundant reminders of death that are typical of medical practice . . . influence how they diagnose and treat patients."<sup>124</sup>

The psycho-social and the spiritual aspects of healthcare become more prominent with every biotechnological advance<sup>125</sup> — this, essentially because of their interconnectedness<sup>126</sup> and goal-sharing of alleviating pain and suffering at all levels,<sup>127</sup> and the further growing realization that scientific research is revealing some "specific biological pathways, notably in the brain, mediating social and psychological processes."<sup>128</sup> Practical effectiveness of good clinical medicine today requires "establishing a

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WHOLE PERSON CARE: A NEW PARADIGM FOR THE 21ST CENTURY 149 (Tom A. Hutchinson ed., 2011).

120. See Solomon & Lawlor, *supra* note 62, at 98; Edmund D. Pellegrino, *Patient and Physician Autonomy: Conflicting Rights and Obligations in the Physician-Patient Relationship*, 10 J. CONTEMP. HEALTH L. & POL'Y 47, 47 (1994).

121. Solomon & Lawlor, *supra* note 62, at 98.

122. See, e.g., Mark Epstein, *THE TRAUMA OF EVERYDAY LIFE: A GUIDE TO INNER PEACE* (2013); Mark Epstein, Op-Ed, *The Trauma of Being Alive*, N.Y. TIMES, Aug. 3, 2013, at SR8, available at [http://www.nytimes.com/2013/08/04/opinion/sunday/the-trauma-of-being-alive.html?\\_r=0](http://www.nytimes.com/2013/08/04/opinion/sunday/the-trauma-of-being-alive.html?_r=0).

123. SUSAN CHATER ET AL., *SEDATION FOR INTRACTABLE DISTRESS IN THE DYING—A SURVEY OF EXPERTS*, 257 (Palliative Medicine 1998). See also Sandhya Somashekar & Juliet Eilparin, *Insurers Directed to Treat Mental Health Issues the Same as Physical Ailments*, WASH. POST, Nov. 8, 2013, at A2 (discussing new final rules — after five years of preparation — under the 2008 Health Parity and Addiction Equity Act and the 2010 Affordable Care Act which direct healthcare insurers to treat coverage for mental health on an equal footing with somatic illness).

124. Solomon & Lawlor, *supra* note 62, at 101, 105-06. See also Gregory Fricchione, *Separation-Attachment Theory in Illness and the Role of the Healthcare Practitioner*, in *WHOLE PERSON CARE: A NEW PARADIGM FOR THE 21ST CENTURY* 45 (Tom A. Hutchinson ed., 2011).

125. See SAM PARNIA & JOSH YOUNG, *ERASING DEATH: THE SCIENCE THAT IS REWRITING THE BOUNDARIES BETWEEN LIFE AND DEATH* (2013); GEORGE P. SMITH, II, *THE NEW BIOLOGY: LAW, ETHICS, AND BIOTECHNOLOGY* (1989).

126. See Liben, *supra* note 61.

127. See SMITH, *supra* note 11, at 61; GEORGE P. SMITH, II, *DISTRIBUTIVE JUSTICE AND THE NEW MEDICINE* (Edward Elgar ed., 2008).

128. COX, CAMPELL & FULFORD, *supra* note 13, at 24.

genuinely human relationship between patient and doctor.”<sup>129</sup> Achieving this can only be accomplished by “considering all facets of the person, including their beliefs (faiths) and spiritual understanding.”<sup>130</sup>

Rather than being completely socialized into a Western medical culture, which predisposes them to “do more” (e.g., investigations, interventions, and uses of new medical technologies),<sup>131</sup> and thus emphasizing “curing and fixing” rather than “healing/bearing witness/being with;” contemporary healthcare professionals need to be more intellectually honest and forthcoming in acknowledging when “death is imminent, inevitable, and perhaps timely.”<sup>132</sup> Patient adjusted care demands — first and foremost — a standard of total honesty between patient and physician<sup>133</sup> — for, without it, there can be no conscious opportunity for informed consent to be operative.<sup>134</sup> When both the healer and the patient are capable of confronting, specifically, their existential fears regarding a terminal medical condition and the mortality that attaches to it,<sup>135</sup> whole person care and the very integrity of *cura personalis* are validated; an appropriate measures may be undertaken in order to alleviate the conditions. Proportional humane medical responses to patient suffering — of whatever character — at the end-stage of life, should be given medically and allowed legally.<sup>136</sup>

A national dialogue must continue over how best to “manage death” at its end-stage.<sup>137</sup> An integral part of this discussion must evaluate humane,

129. *Id.*

130. *Id.* See Antje Du Bois-Pedain, *The Duty to Preserve Life and Its Limits in English Law, in THE SANCTITY OF LIFE AND THE CRIMINAL LAW: THE LEGACY OF GLANVILLE WILLIAMS* 296, 305-09 (Dennis J. Baker & Jeremy Horde eds., 2013) (observing a “morality of care” is imposed upon a physician to accept patients as “concrete individuals”). See also Sulmasy, *supra* note 63, at 195-96.

131. See STANLEY J. REISER, *TECHNOLOGICAL MEDICINE: THE CHANGING WORLD OF DOCTORS AND PATIENTS* (2009). For some, questing for immortality has led medical technology to explore cryonic preservation as an “alternative” to accepting the finality of death. See George P. Smith, II, *Pathways to Immortality in the New Millennium: Human Responsibility, Theological Direction, or Legal Mandate*, 15 ST. LOUIS U. PUB. L. REV. 447, 459-61 (1996).

132. Solomon & Lawlor, *supra* note 62, at 104.

133. See THE PRESIDENT’S COUNCIL ON BIOETHICS, *supra* note 38, at 217. See EDMUND D. PELLEGRINO & DAVID C. THOMASMA, *A PHILOSOPHICAL BASIS FOR MEDICAL PRACTICE: TOWARD A PHILOSOPHY AND ETHIC OF THE HEALING PROFESSION* (Oxford Univ. Press, 1981).

134. GEORGE P. SMITH, II, *The Vagaries of Informed Consent*, 1 IND. HEALTH L. REV. 111, 113 (2004). See Jay Katz, *Informed Consent—Must it Remain a Fairy Tale?*, 10 J. CONTEMP. HEALTH L. & POL’Y 69, 70 (1994).

135. See Edmund D. Pellegrino, *Character, Virtue and Self Interest*, 5 J. CONTEMP. HEALTH L. & POL’Y 53 (1989).

136. See EDMUND D. PELLEGRINO & DAVID C. THOMASMA, *THE PATIENT’S GOOD: THE RESTORATION OF BENEFICENCE IN HEALTH CARE* viii (1988).

137. See SMITH, *supra* note 23; Edmund D. Pellegrino, *Euthanasia and Assisted Suicide, in DIGNITY AND DYING: A CHRISTIAN APPRAISAL* 105 (John F. Kilner et al. eds., 1996). See FIONA

compassionate approaches, together with efficacious medical treatments which seek to balance vitalism, or sanctity of life, with quality of life as consistent with established or sound medical practices.<sup>138</sup>

In the United States, it is estimated that spending on end-of-life care is between 10 to 12 percent of overall spending for healthcare.<sup>139</sup> Between 25 to 30 percent of all Medicare benefits are expended for end-of-life care.<sup>140</sup> There is a significant volume of evidence which substantiates the conclusion that, in multiple healthcare settings such as hospitals and in nursing homes, end-of-life care is cost effective.<sup>141</sup>

The central ethical question in death management remains: namely, the extent to which “marginally beneficial” treatment should be offered and then maintained.<sup>142</sup> Because of the inherently subjective nature of weighing costs versus benefits and considering over-utilization or under-utilization of medical care and treatment, a “just right” mean between these options will be exceedingly difficult to set or establish.<sup>143</sup>

The doctrine of medical futility is an efficacious framework for principled decision-making within the medical profession.<sup>144</sup> Acceptance of this doctrine as a construct for medical decisions allows — in turn — for a greater openness to utilize palliative sedation. When necessary to accommodate the best interests of a patient and to alleviate refractory pain

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RANDALL & ROBIN DOWNIE, *END OF LIFE CHOICE: CONSENSUS AND CONTROVERSY* (Oxford Univ. Press ed., 1st ed. 2009).

138. See *PARTNERS IN PALLIATIVE CARE: ENHANCING ETHICS IN CARE AT THE END OF LIFE* (Mary Beth Morrissey & Bruce Jennings eds., 2013). See Pellegrino, *supra* note 115; Shepherd, *supra* note 91. See *IN DEFENSE OF HUMAN DIGNITY: ESSAYS FOR OUR TIME* (Robert P. Kraymack & Glenn Tinder eds., 2003). See Cathy Lynn Grossmann, *A Look at Religion's Effect on Minority End of Life Views: Pew Research Center Survey Highlights Black and Hispanic Preferences for Aggressive Treatment in the Face of Incurable Disease and Great Pain*, WASH. POST, Nov. 30, 2013, at B2.

139. *PARTNERS IN PALLIATIVE CARE: ENHANCING ETHICS IN CARE AT THE END OF LIFE*, *supra* note 138, at 111.

140. *Id.* at 112.

141. *Id.* at 119.

142. *Id.* See also PELLEGRINO, *supra* note 60, at 108.

143. *PARTNERS IN PALLIATIVE CARE: ENHANCING ETHICS IN CARE AT THE END OF LIFE*, *supra* note 138. See also Pellegrino, *supra* note 60, at 108.

144. See Smith, *Utility and the Principle of Medical Futility*, *supra* note 54, at 6. See C. Christopher Hook, *Medical Futility*, in *DIGNITY AND DYING: A CHRISTIAN APPRAISAL* 84 (John F. Kilner et al. eds., 1996) (when treatment is judged futile by competent medical authority, there is an “obligation to refrain from demanding” such treatment be provided). See Philip G. Peters, Jr., *When Physicians Balk at Futile Care: Implications of the Disability Rights Law*, 91 N.W. U. L. REV. 798, 800 (1997) (explaining preferable approaches to futility cases). See also Meir Katz, *When Is Medical Care “Futile?” The Institutional Competence of the Medical Profession Regarding the Provision of Life-Sustaining Medical Care*, 90 NEB. L. REV. 1, 5-7 (2011).

and suffering, compassion and common sense, then, become the cornerstones of end-of-life management, care, or treatment.<sup>145</sup>

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145. See George P. Smith, *Gently into the Good Night: Toward a Compassionate Response to End-Stage Illness*, 22 TEMP. POL. & CIV. RTS. L. REV. 476, 490-92 (2013). As Dr. Edmund D. Pellegrino has observed: "a dignified death is one in which the suffering person takes advantage of all the measures to relieve pain and ameliorate the things that cause a loss of imputed dignity but also that his or her innate dignity remains . . . which is at the root of our existence as creatures." Pellegrino, *supra* note 60, at 113. See also Cass Sunstein, *The Right to Die*, 106 YALE L. J. 1123, 1163 (1997); Magnusson, *supra* note 81, at 560.

